



Speaking from Experience Arthritis in Childhood

Transcript for chapter 5 of 9: School

Peter and Toni have a daughter, 14yrs, with arthritis: Schooling's really important, you have to have that, you have to go and discuss it with the teachers and let them know what's going on, because they're going to be with your child for 6-7 hours of the day. So, when you're not there, they're going to be looking after your child for you.

Conrad and Doune have a daughter, 7yrs, with arthritis: We've adopted very different approaches over the last two years. The initial approach that we adopted was really not to tell them much about her condition at all, because she actually started off relatively well. I didn't want her to be isolated and singled out as a child with arthritis, when it didn't really seem that serious. But, we're actually now having a lot more communication with the school and keeping them a lot more informed about the condition.

Sharyn has a son, 12yrs, with arthritis: The worry for me was him going on to high school. Here's this environment with four times as many kids, and Craig just a number - just one of 1200 kids. I started to panic then.

Conrad and Doune: There's actually an integration support system in place now, where we have regular meetings with the teachers and the principal. For some of those meetings, we'll actually involve someone from the Arthritis Foundation, because there's going to be lots of ongoing issues at the school, and we need to develop more strategies with the school for Claire to be included more into social activities. So that she can survive lunch times, basically.

Sharyn: I went and spoke with his year 7 coordinator, who was fabulous. She said, "Look, I hear what you're saying. I'm really pleased to meet you. Can you go and write all those things down and give it to me in the next couple of days? And I'll circulate it amongst all his teachers." Which I did and then I got a phone call the next day from the social worker at school saying, "I've got this great letter here. Thanks for taking the time to write it. I'm going to personally make sure I know who Craig is".

Michelle and David have a daughter, 5yrs, with arthritis: I actually gave Sophie's teacher, and put into Sophie's file, a short article about juvenile arthritis. I thought, it wasn't too much to read, so you could read it very quickly. Apparently, that's been passed around to all of the teachers in the junior part of the school and to the PE teacher.

Conrad and Doune: It's been really important to educate them that she doesn't have to sit out of all sporting activities; that she needs to be included. That she will take herself out of the activity... They think they're helping by making her sit around all the time. Again, this has taken quite a long time, to develop the relationship to educate them enough about the condition. Because we've had devastating incidents where we've found out she's been made to sit out for weeks on end of games.

Peter and Toni: Instead of being intimidated by the teacher's position, they need to get over that and make sure the teacher understands their situation and doesn't overlook them



and not take notice of what the problem is. It's an assertiveness thing. It's a balance between being assertive and not being seen to be cheeky, I guess.

Conrad and Doune: It took us a while to work this out, but she couldn't keep up with the kids games, the running... the game would be over there, then it would be over there and over there, and Claire just couldn't keep up. So, she was spending her lunch time and her game time just walking around with her teacher on yard duty, because at least she was in contact with someone. And then, as she was in grade one, she'd see the younger children that she could actually keep up with and manage. And so she was always mucking around with preps and kids who were slower.

Sharyn: I think he knows his limitations, sport wise. So, he's not going to be school captain of the sports team. A lot of people say that Craig's really funny and he's got a real personality and sense of humour. And I think that's where he's developing himself to have friendships through that.

Robert 18 yrs – has Polyarticular Arthritis: VCE I found was a very stressful year, for the workload. Which really reacted on my joints quite heavily. Stress really aggravates my joints and flares them up, which really makes it harder to try to cope with doing my work.